

## Ethical theory and medical ethics: a personal perspective

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**Ethical physicians need to share their biases and prejudices and articulate alternatives and also be tolerant of the decisions of their patients and families.**

I believe that I am a moral, caring, dedicated doctor working with children and parents who are often faced with ethical problems of large and small dimensions. There is no question that these decisions should be ethical, but, in general, I find ethical theory of little day-to-day use. Indeed, even when an ethicist joins me in a discussion of "What should I do?", or more appropriately, "What should I advocate be done?", I usually find their additions to the discussion wanting. Ethical theory gives guidance but does not seem to provide sufficient help in decisions for the individual case:

- What will be best for the infant with spina bifida while still in utero? Termination of the pregnancy? Birth and long-term care?
- What is best were that same child already born with a high paraplegia and hydrocephalus?
- What is best for the infant with a major malformation of the brain and uncontrollable seizures whose only hope for controlling the seizures is removal of half of the brain?
- What is best for the family in each of these situations and the many others I have encountered?
- What is best for society?

I have been called a Hegelian pragmatist, although my knowledge of Hegel is minimal. I think that the term pragmatist is a badge of honour, because, on the front lines of clinical decision-making, I do not have the philosopher's luxury of days or weeks for managing words. As a pragmatic doctor, I am forced to be a person of action or inaction. I must make a decision and advocate for the position I take.

I am clearly a utilitarian, as I strive to produce the greatest good for the greatest number, but that number is constrained to the family and child at hand. The child's good clearly has primacy, but is treatment always good for a child who

is profoundly damaged? I would also like to consider society's good, as I am concerned about society's investment in a single child or person. I am constrained by Lamm's<sup>1</sup> arguments that "everything we do in a budget prevents us from doing something else we care about".

I, of course, factor in the possible outcomes, and the risks and benefits of each decision, but I am always dealing with one child and one family, and therefore the outcomes of treatment are always binary, such as whether the child will become infected or not, and whether the operation will be successful or unsuccessful. It is the probability of these outcomes that has a numerical value that is not always predictable with sufficient precision.

And yet, as I try to help families decide on an operation or a course of treatment, I worry that I am being too directive, too paternalistic. As director of the Birth Defects Clinic, I was a strong advocate for early operation on the newborn with spina bifida. I have recently written about the arrogance of my approach to the early treatment of spina bifida.<sup>2</sup> Several of the young women in their early 20s, who are among my most successful patients, recently told me they wished they had never been born. Should my discussions with their parents when my patients were newborn have been more neutral, less paternalistic and directive? Was I correct in advocating their early treatment? Did their survival truly increase the "greatest happiness for the greatest number"? Can non-intervention and a hope for early death not increase the family's and perhaps even the child's happiness? In these and other operations on children who are likely to remain severely handicapped and considerably retarded, I wonder if the operation is really in the best interest of the child and the family. Would non-intervention and a hoped for early death not have increased everyone's happiness? Would that early death not have

saved society enormous expense, and thereby increased the "happiness" for a greater number? If an early death was determined to be the best outcome, then would not the greatest happiness be achieved by assisting in that early death?

This is the utilitarian side in me. I try to suppress it in reaching my decisions, but it is there, in the shadows. It does not alter my commitment to the child, but nags at my conscience. These thoughts are not voiced to the family, but to my inner self and to my students as we go through the process of deciding what to advocate—or should I just advise? Should I tell the family that it is permissible to decide not to go through with the operation? That it is not unreasonable to hope for an early death for the child? I do not know what decision will bring "the greatest happiness", nor to whom that happiness will accrue. Neither do the families, who are faced with the decisions, but they, nevertheless, must decide, and I must help them to make the best decision.

But do I know what it is like to be physically handicapped or retarded? I knew, or at least I thought I knew, what I would want for myself or for my child. What I would want, however, is not pertinent. We are faced with what we have been given—or what someone else has been given. Families usually rise to what I consider terrible, ongoing adversities. I am awed by those who continue to care lovingly for the child who is profoundly disabled and who does not interact with them<sup>3</sup> or with the environment. I empathise with the parent who is constantly showing love, care and compassion without the immediate positive feedbacks and rewards that we parents have come to expect.<sup>4</sup> I am overwhelmed by the parents of the blind child, born at 1½ pounds, who spent 4 months in the nursery, but who, under their nurturing care, is a beautiful 6-year-old with only occasional seizures. I am reminded of the words of Deborah Kent,<sup>5</sup> who herself is blind:

When I was growing up people called my parents, "Wonderful". They were praised for raising me "like a normal child". As far as I could tell, they were like most other parents in my neighborhood, sometimes wonderful and sometimes very annoying. And from my point of view I wasn't like a normal child, I was normal.

On reading this, I again realised the bias and prejudices that underlie my ethics and my decision making. As I try to factor quality of life into my advice, I again realise how limited is my own

view of other people's quality of life. Families turn to doctors for advice and counsel about what is best for themselves or for their child. Do we, as doctor-advisers know? How can we help them? I search for some truth, for the greatest good for the greatest number. But the utilitarian principles do not completely satisfy my need as I am helping one family to decide.

Kantian ethics mandate that I never treat an individual as a means to an end. I do not think I ever have. I always try to respect the family and the individual, but respect does not help in decision making. It means we treat people only with their consent, but their consent usually is acquiescence and is based on the information we have provided. This information contains all of our spoken and unspoken biases, minor biases in the words we have perhaps inadvertently chosen, such as "severe", and in the body language we use in the discussions.

Families rarely come to me solely for information so that they can make an autonomous, informed decision. Information can be obtained from libraries and now increasingly from the internet, with all the biases and prejudices of those who have posted it. Patients and families come to me for an opinion, or for a second or third opinion. I tell them that these are my opinions—not necessarily facts—and also why I hold them. Providing my opinion is my form of respect and underlies my ethics. I always respect the autonomous decisions of the family, but only if those decisions are reasonable and within the limits of my paternalistic, philosophical boundaries.<sup>6</sup> Does this represent true autonomy?

Some ethicists turn from the important issue of what to do, to the issue of whom to ask, to who should decide, as if that were a substitute for what should be decided. Who should decide is not a substitute; it is merely a segue into an easier discussion.

Of course, the patient or the surrogate should decide, as long as they make the "right" decision. The right answer or the right decision, however, depends on the question being asked, and on how it is asked. When the family of a patient in a permanent coma after a stroke or a head injury is asked, "Would you like us to turn off the respirator?", you are likely to get a different answer than if the question is stated as, "We think that the respirator is merely postponing his inevitable death, and believe that it is kinder to turn it off and end his suffering. If you object, tell us." In either situation, the goal of doctors is to do what they perceive is best for the patient and the family. With the first question, the decision (and any guilt or

blame) is placed on the family member. With the second question, all that is asked is acquiescence, a far less onerous burden. Of course, such a discussion is never only one question in length, but which is the better way to structure the discussion? When asked the second way, who has made the decision? As the treating doctor, I feel that relieving family guilt is a part of my role. This, I believe, is both beneficent and paternalistic, but what does it say about autonomy? Is the bias incorporated in this approach to the question of turning off the respirator ethical? Would I trust all other doctors to do it with the same care and compassion? I doubt it.

Do families or people really want total autonomy? I do not think so. How are they to make autonomous decisions when, in general, they only know the facts as I have informed them? They have even less knowledge than I of what the future will bring for their child or for their family or of how they will cope with this future. Can anyone know what it would be like to grow up deaf, or retarded or with severe disabilities? Can I help families to understand when I have never been there? Even using the term "severe" biases the argument, for does the child know the word "severe"? Or, like Deborah Kent, will the child consider blindness normal? Rules of respect are a part of my discussions with families, but do not help me or my patients in our decision-making process.

My approach to patients is clearly paternalistic and somewhat directive. I follow the duty never to lie, but the truth can be unclear and a semivariable commodity, situational and personal. The truth telling is my truth telling, shaded by my "less strong" duty to tell the whole truth. Part of my paternalistic or maternalistic compassionate role is to tell the truth as I define it, in the least harmful fashion.

I have a duty, and a legal obligation, not to kill. But letting die is permissible. This dichotomy greatly bothers me as I watch the child and the family suffer, not necessarily with pain but with the gradualism of an inevitable death occurring over days and weeks. The distinction between killing and letting die is deeply rooted in ethics and personal beliefs, but watching a person die by inches seems cruel when modern medicine has given us both the methods to end suffering and the means to keep it from misuse. I worry that theory has obscured reality and question why the greater good is not served by the quick and painless death that rules and rule-based ethics have proscribed.

I do not believe that my outlook is derived from any specific religious background, but clearly is grounded in

religious traditions. I object to the idea that philosophers have brought an intellectual rigour to the discussion. Indeed, my regret is the distance that they have, in general, maintained from the bedside fray, from the individual decisions that are so often made.

Thus, in summary, I find not even one of the theories or philosophies taught by ethicists wholly satisfying or completely useful when applied to individual patients. The moral and ethical physician must take cognisance of and derive elements from each theory. If there was only one pathway to truth, and only one truth, life may be easier and less challenging. But then that pathway may not be appropriate for everyone and every decision.

I advise my students to attempt to be virtuous in the Aristotelian sense; to follow the rules and to be aware of their rights, duties and obligations to themselves, to their virtue and to that of their patients. I advise them to be sensitive, caring and compassionate in the maternalistic sense, dedicated to their profession and to those they serve, guiding their patients in the best directions, in a paternalistic fashion. I suggest that younger doctors should sandpaper their fingertips, be more sensitive to the nuances of each situation and to the family's cultural background and beliefs. They can then help the family or person, being better equipped to make their own best decisions.

Ethical physicians need to be attuned to the differences and alternatives to the decision they prefer, share their biases and prejudices and articulate the alternatives, and be tolerant, in carefully defined limits, of the decisions of patients and their families.

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